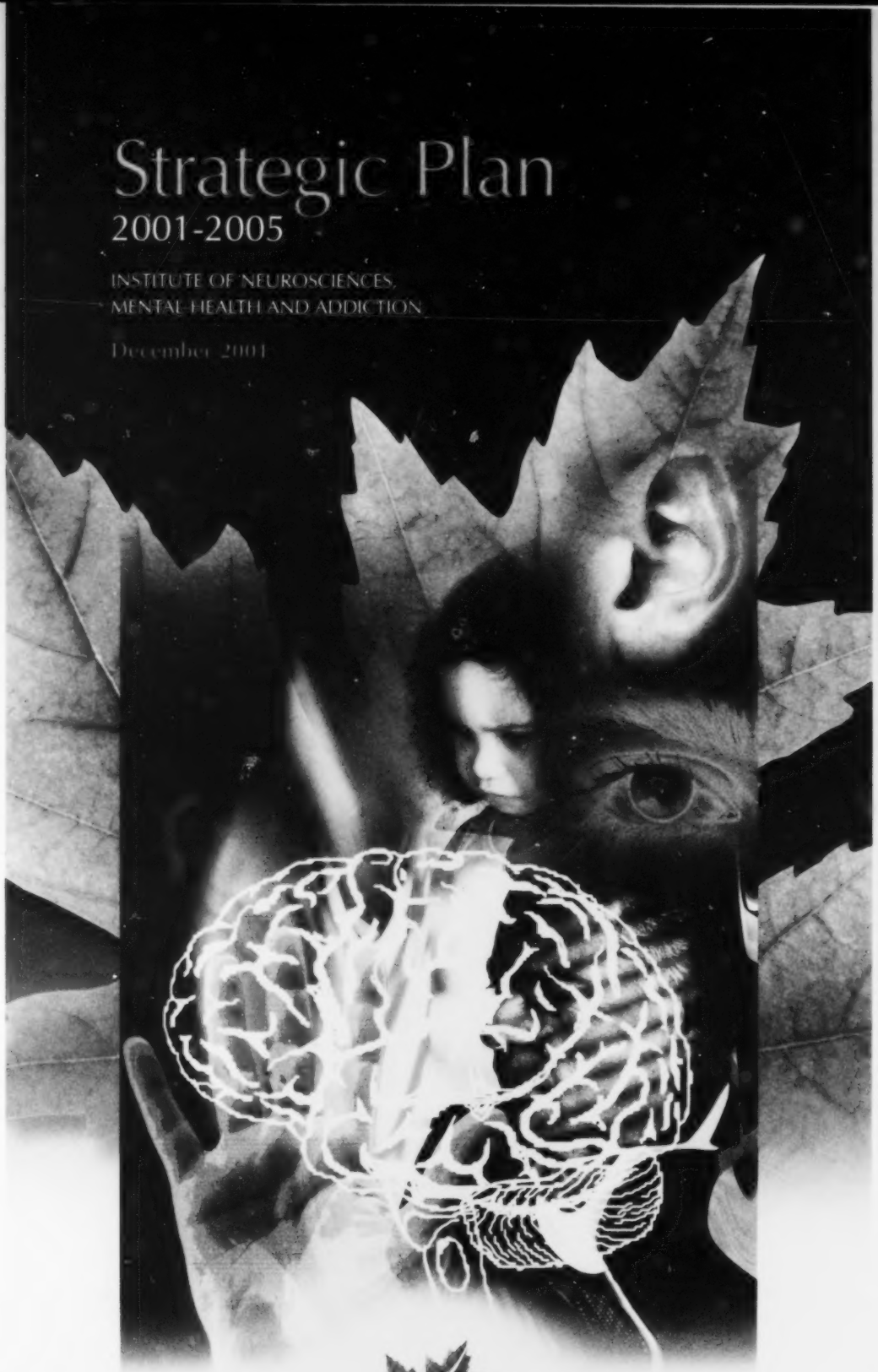
Strategic Plan
2001-2005

INSTITUTE OF NEUROSCIENCES, MENTAL HEALTH AND ADDICTION

December 2001



CIHR IRSC
Canadian Institutes of Health Research

Canada

Staff Members

103-05142/

Dr. Rémi Quirion
Scientific Director

Dr. Richard Brière
Assistant Director

Rania Jabr
Executive Secretary

Astrid Eberhart
Assistant Director, Partnerships

Jennifer Bethell
Project Officer

Institute Advisory Board Members - INMHA

Dr. Anthony Phillips
(Chair), Professor, Psychiatry, The University of British Columbia

Dr Gordon DeVol
Bioethicist and Assistant Professor of Psychiatry, Centre for Addiction and Mental Health, University of Toronto

Dr. Jack H. Jhamandas
Professor and Canada Research Chair in Medicine, University of Alberta

Dr. Stanley Kutcher
Professor and Head of Department of Psychiatry, Dalhousie University

Dr. Robert Ladouceur
Professor, School of Psychology, Laval University

Dr. Alain B. Lesage
(Vice-Chair), Adjunct Researcher, Psychiatry, Research Centre Fernand-Séguin, Louis-H. Lafontaine Hospital

Dr. Michel Maziade
Full professor of Psychiatry, Research Centre, Laval University

Dr. Bruce McEwen
Head, Neuroendocronology, The Rockefeller University, New York

Dr. Lisa McKerracher
Associate Professor, Pathology and Cell Biology, University of Montreal

Dr. Roberta M. Palmour
Professor, Psychiatry, McGill University

Dr. Marlene Reimer
Associate Professor and Associate Dean, Nursing, University of Calgary

Dr. Michael Salter
Professor, Physiology, The Hospital for Sick Children

Dr. Peter Scholefield
Volunteer, Etobicoke, ON

Dr. Eric W. Slagle
Adjunct Professor, Sociology and Public Health Sciences

Dr. Martin J. Steinbach
Distinguished Research Professor of Psychology and Biology, York University and Professor, Ophtalmology, University of Toronto

Mr. Philip Upshall
Volunteer, Guelph, ON

CIHR Governing Council

Dr Alan Bernstein
(Chair), President, Canadian Institutes of Health Research

Dr. Denise Alcock
Dean, University of Ottawa

Dr. Stephanie Atkinson
Professor, McMaster University

Dr. Françoise Baylis
Associate Professor, Dalhousie University

Dr. Ruth Collins-Nakai
Health Care Consultant

Dr. Alastair Cribb
Professor, University of Prince Edward Island

Dr. Jean Davignon
Director, Institut de recherche clinique de Montréal

Mr. Robert Gauthier
President and CEO, St. Boniface General Hospital

Mr. Ian Green
(ex-officio), Deputy Minister, Health Canada

Dr. Philippe Gros
Professor, McGill University
Dr. Kevin Keough, Chief Scientist, Health Canada

Dr. Malcolm King
Professor, University of Alberta
Mr. Steven Lewis, Partner, Access Consulting Ltd

Dr. Victor Ling
(Associate Vice-Chair), Vice-President, BC Cancer Institute

Dr. Louise Nadeau
(Vice-Chair), Professor, University of Montreal

Dr. David Naylor
Dean of Medicine and Vice Provost, University of Toronto

Dr. Rodney J. Ouellette
Director, Dr. Georges L. Dumont Hospital, Moncton

Dr. Sarah Stabo Prichard
Professor, McGill University

Dr. Carol Richard
Professor, Laval University

Mr. Joseph Rotman
Roy L. Capital Corporation

TABLE OF CONTENTS

		Page
PREFACE		1
EXECUTIVE SUMMARY		3
1.	INTRODUCTION	7
2.	FOUNDATIONS OF THE STRATEGIC PLAN	10
3.	BURDEN OF DISEASE	13
4.	STRATEGIC PRIORITIES	26
5.	RESEARCH PRIORITIES	28
5.1	Capacity for Innovation in Research in Neurosciences, Mental Health and Addiction	28
5.1.1	Training	28
5.1.2	Strategic Initiatives	31
5.1.3	Emerging Areas and Unique Opportunities	35
5.1.4	Research in Bioethics	39
5.2	INMHA's Presence on the International Stage	40
5.3	Linkage and Exchange – Knowledge Translation	42
6.	ENABLING FOUNDATIONS	45
6.1	Collaborative Partnerships	45
6.2	Organisational and Operational Structure	47
7.	FUTURE CONSIDERATIONS	53

PREFACE

Like the Canadian Institutes of Health Research (CIHR), the Institute of Neurosciences, Mental Health and Addiction (INMHA) is unique in the world. For the first time, experts in basic and clinical sciences, health services and population health research interested by the three broad domains of the INMHA are grouped together under a single entity.

Over the past year, we have come to appreciate not only the challenges that we must face in such a unique grouping of health research domains but also the tremendous opportunities that we can embrace. Advances in understanding how the brain and the mind function provide the basis for seizing opportunities that will help further our knowledge. It is our hope that this knowledge will be applied to the development of innovative, ethically responsible treatments and improved health care services for neurological, mental and addictive disorders. This knowledge will also lead to a better understanding of the broader socio-cultural phenomena associated with these disorders.

The Strategic Plan that we present in the following pages sets forth the framework that will help define and guide the INMHA's major health research initiatives over the next few years. Since December 2000, the INMHA has participated in Open Forums at close to twenty-five universities across Canada. These meetings enabled members of the INMHA and the scientific community to discuss issues, interests and opportunities in research and training in the various fields covered by the Institute. In June 2001, we also held a first, highly successful meeting with various non governmental and volunteer health organizations within the domains covered by our Institute. The results of these discussions are reflected globally in the Strategic Plan, as is the input obtained from other INMHA stakeholders, in particular, members of the Institute Advisory Board, pharmaceutical industry and biotechnology firms, national and provincial agencies, CIHR staff and other Institutes.

The efforts required to fulfill our mission and achieve our goals are as challenging as the mandate of the INMHA. Building capacity, training the next generation of Canadian scientists and addressing questions on health care ethics are certainly key efforts. We must also ensure the development of partnerships with stakeholders who share our belief that novel collaborations and sustained support are required to transform the INMHA's vision into reality. It is our belief that all our initiatives must be inclusive and innovative, and promote collaborations among specialists in the domains covered by the INMHA. This is true not only at the national level but also at the international level.

I thank all our stakeholders for contributing to the development of the INMHA's first Strategic Plan. I hope that each one of you will feel that it is **your plan** and that the INMHA is **your Institute.** The INMHA's overall goal is scientific excellence and ethically responsible research that leads to improved treatments and a better quality of life for all Canadians. Your support is absolutely essential in ensuring the full realisation of the Strategic Plan and the unique potential of the INMHA.

Rémi Quirion, Ph.D.
Scientific Director
Institute of Neurosciences, Mental Health and Addiction

EXECUTIVE SUMMARY

The foundation upon which both the CIHR and its Institutes seek to fulfill their mandates is innovation. The unique grouping of the scientific and health research domains covered by the Institute of Neurosciences, Mental Health and Addiction (INMHA) is itself an innovative concept that translates into a new context for research. It presents challenges and exciting opportunities, both of which are addressed in this Strategic Plan.

The **vision** of the INMHA is that innovative research will provide new knowledge of the biological and socio-cultural processes underlying neurological, mental and addictive disorders. As such, the INMHA's **mission** is to foster excellence in innovative, ethically responsible research in Canada that aims to increase our knowledge of the functioning and disorders of the brain and the mind, the spinal cord, the sensory and motor systems, as well as mental health, mental illness and all forms of addiction. The INMHA seeks to translate this new knowledge into a better quality of life for all Canadians through improved health outcomes, health promotion and health care services.

INMHA's **goals** focus on key elements of the new context for health research - internationally recognized research, trans-disciplinarity, collaborative partnerships, accountability – and on aspects related to the specificity of the Institute. The INMHA is well positioned to develop close collaborations with various CIHR Branches and Programs, other Institutes, a number of governmental, non-governmental and volunteer health organizations, and pharmaceutical and biotechnology firms. The INMHA can also make an important contribution to civil society through a greater understanding of the discrimination, prejudices, social problems and ethical issues associated with the illnesses and disorders coming under the umbrella of the INMHA. The INMHA's **values** underscore its commitment to the support of excellence in research and recognize the opportunities that arise from the diversity of its disciplines as well as the importance of expanding beyond traditional approaches in promoting scientific development.

Strategic Priorities

The INMHA's strategic priorities are designed to lead to the development of innovative cross-Institute and cross-pillar approaches to research in neurosciences, mental health and

addiction. They will also help establish strategic partnerships with its various stakeholders that maximize financial, technological, research infrastructure and human resources investments in health research.

The following priorities will help the INMHA develop its research agenda:

1. **To foster and develop a capacity for innovation in research in neurosciences, mental health and addiction that will strengthen Canada's health research milieu in these fields and enhance its competitive position on the international scene. Four areas of focus have been identified:**

   1.1 ***Training***: to build research capacity by participating in the CIHR Training Grant Program and by creating opportunities for short-term training for clinician scientists, mid-career researchers, research associates and other research personnel. The INMHA has also established the bi-weekly BrainStar Award as a way of recognizing the unique contribution of trainees.

   1.2 ***Strategic initiatives*** Four have been identified:

   - Study of first episode events in neurological and mental illnesses, and in addiction;
   - Research in co-occurrence of brain disorders with other health problems, and research in co-morbidity;
   - Regenerative medicine – neurosciences:
     - Brain and spinal cord repair;
     - Vision and hearing losses;
   - Nicotine addiction and tobacco abuse.

   The INMHA will also participate in the CIHR's strategic initiative in Rural and Northern Health Research.

   1.3 ***Research in emerging areas or where unique opportunities arise*** The INMHA will promote and support New Emerging Team (NET) Programs, in partnership with other organizations.

The four themes which the INMHA has identified for 2001-2002 are: discrimination and stigma; understanding the placebo effect; neurodevelopment and early life events; and computational neurosciences and artificial intelligence.

*1.4 **Research in bioethics*** The INMHA will work with CIHR in building research capacity in health care ethics to address the ethical challenges associated with research in the domains covered by the INMHA.

2. **To develop the INMHA's presence on the international stage through joint research, training and funding initiatives with scientific and research funding agencies in other countries.**

3. **To promote linkage and exchange between the research community and various levels of decision-makers and users of research results through structured efforts aimed at knowledge translation.**

The INMHA will collaborate with the CIHR in developing a framework for contributing to public policies and programs at the municipal, regional, provincial and national levels that will help create an environment conducive to the development of the CIHR and its Institutes.

Enabling Foundations

The INMHA is placing emphasis on two key functions that will help structure and support its research priorities, and ensure effective management of its resources.

1. **To pursue and sustain collaborative partnerships that will enable the INMHA to share, develop, obtain or leverage resources required to accomplish its mandate.**

2. **To establish an organisational and an operational structure that will enable the INMHA to accomplish its goals.** Three components have been identified:

2.1 Implement an effective governance, accountability and management structure and process. The number of domains covered by the INMHA means that the Institute Advisory Board must speak with a single voice in promoting and developing research priorities.

2.2 Develop and sustain structured communication efforts aimed at informing and gaining an understanding of the health, ethical and research issues related to the INMHA's domains. The INMHA is developing a Communications Strategy and will work with its stakeholders, particularly non governmental and volunteer health organizations, in raising public awareness and developing innovative and effective means to reduce discrimination and stigma.

2.3 Develop a framework for gathering, maintaining and accessing relevant and reliable health and research information in the fields of interest of the INMHA.

1. INTRODUCTION

The foundation upon which both the CIHR and its Institutes seek to fulfil their mandates is innovation. The ability of an organization to innovate is enhanced when organizational, collaborative and public policy measures intertwine[1]. Innovation therefore has multiple dimensions and refers not only to acquisition and application of new knowledge or technology, which are most often associated with research and development efforts, but also to process and organizational changes.

The CIHR structure itself is unique and innovative in its concept and scope. In essence, it aims to redefine scientific, governmental, volunteer organizations and industry relationships within a framework[2] that integrates the determination of a national health research agenda with the creation of new knowledge, capacity building and knowledge translation. As such, the CIHR and its Institutes are creating a new context for health research in Canada.

The Institute of Neurosciences, Mental Health and Addiction (INMHA) of the CIHR is a reflection of the new Canadian context for research. The INMHA concerns itself with research on the functioning and disorders of the brain, the spinal cord, the sensory and motor systems, and the mind. The burden of disease in terms of the social, economic and health care costs associated with these disorders and related illnesses are staggering and there are indications that the number of people affected either directly or indirectly will continue to increase in the years to come.[3]

The INMHA is unique in that, based on recent discoveries, it was rightly decided by the interim Governing Council of the CIHR to group into a single Institute, all aspects of research dealing with Brain-Mind relationships inclusive of the four pillars of the CIHR. The four pillars are biomedical, clinical, health services and population health research. It is a daunting endeavour, but the INMHA can transform this endeavour into a unique opportunity for creating a context for innovation in health research in the domains covered by its mandate.

---

1 Reference: *Annual Innovation Report*, The Conference Board of Canada, 1999.

2 CIHR's Innovation Platform for Health and Wealth, March 20, 2001.

3 The Global Burden of Disease: A comparative assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Harvard School of Public Health, 1996.

STRATEGIC FORCES

INMHA's strengths

Combined individual, multidisciplinary and trans-disciplinary potential

The INMHA benefits naturally from the strength of neurosciences research in Canada. It can also harness enormous energy from the diversity of its multiple domains and the breadth of its research in biomedical, clinical, health services and population health spheres, all of which address themselves well to the various disorders and illnesses covered by the INMHA. The potential interactions among such a number of different domains facilitate the development of creative and innovative approaches to research and its application.

Scientific and research opportunities

Recent and expected advances in health research, including molecular biology, genetics, behavioural sciences and medical imaging, converge to create extraordinary opportunities for research in the Brain-Mind relationship. New knowledge about the structure and functioning of the brain in its various biological and socio-cultural aspects will help expand existing research boundaries.

Potential for partnerships

The size and diversity of the INMHA stakeholder communities present a potential for the creation of a number of new partnerships. As well, synergy between stakeholders who would otherwise have had little or no contact is more easily created. The nature of the domains covered by the INMHA also facilitates multi-Institute partnerships and collaborations.

INMHA's challenges

Research priorities

Determining and pursuing research priorities when faced with limited resources is difficult, and it is even more so in the context of the broad mandate of the INMHA. In establishing its priorities, the INMHA must not only take advantage of Canada's strengths in the domains covered by the Institute, but it must also pursue emerging or unique opportunities that arise and develop under-

recognized areas. Its research priorities must also be coherent with the overall goals and the overarching themes of the CIHR.

In defining and developing its research priorities, the INMHA must therefore bring its various disciplines together and work strategically with a diverse group of stakeholders in selectively pursing opportunities.

2. FOUNDATIONS OF THE STRATEGIC PLAN

Mission

The mission of the INMHA is to foster excellence in innovative, ethically responsible research in Canada that aims to increase our knowledge of the functioning and disorders of the brain, the mind, the spinal cord, the sensory and motor systems, as well as mental health, mental illness and all forms of addiction.

The INMHA seeks to translate this new knowledge into a better quality of life for all Canadians through improved health outcomes, health promotion and health care services.

Strategic goals

To accomplish its mission, the INMHA will:

- promote and support excellence in peer-reviewed, internationally recognized and ethically responsible research in the domains of the Institute, including co-occurrence with other health problems;
- encourage trans-disciplinary research in order to facilitate knowledge transfer aimed at developing and improving health care treatments and services;
- ensure the training and support of the next generation of Canadian scientists in all aspects of neurosciences, mental health and addiction by promoting and sustaining the development of trans-disciplinary programs of research and training;
- work with non governmental and volunteer health organizations, municipal governments and other interested stakeholders to reduce the discrimination and prejudices associated with neurological and sensory disorders, mental illnesses and addictions;
- promote the mandate of the INMHA and its contribution through effective communication with all sectors of civil society;
- work with the Government of Canada, municipal, provincial and territorial governments, members of the scientific community, non governmental and volunteer health

organizations, foundations and all Canadians to ensure that sufficient human and financial resources, consistent with the burden of disease of the disorders covered by the INMHA, are made available to the Institute in order to enable it to achieve its goals;

- interact with all stakeholders to identify research priorities, establish partnerships and undertake collaborative activities.

Vision and values

The INMHA believes that innovative, ethically responsible research will provide new knowledge of the biological and socio-cultural processes underlying neurological, mental and addictive disorders. It also believes that a comprehensive approach to research will enhance the quality of life of Canadians suffering from illnesses covered under the broad mandate of the Institute through improved prevention, diagnosis and treatments.

In pursuing its strategic goals, the INMHA has adopted the following guiding principles as values. The INMHA:

- is committed to the support of excellence, scientific integrity and ethics in research that meet the highest international standards;
- cultivates an understanding of the diversity of the multiple disciplines covered by the INMHA mandate in order to expand beyond traditional approaches to research;
- affirms the importance of research and knowledge translation as means of making a difference in the lives of people who are experiencing or who are at risk for the disorders and illnesses of concern to the INMHA;
- takes advantage of the latest advances in research methodology and information technology;
- recognizes that the development of indicators of research outcome is important in determining the impact of research upon the health of Canadians;
- promotes frank and rigorous scientific and public debate on issues and ideas emanating from all of the INMHA's domains;

- fosters collaborations with its stakeholders to create a common commitment to the goals of the INMHA;
- adopts ethical, transparent and effective governance and management processes that establish the INMHA's credibility and strengthen its organizational capacity;
- acknowledges its accountability to the Governing Council of the CIHR, the Government of Canada and Canadians for the funding received and the accomplishment of its goals.

3. BURDEN OF DISEASE[1]

The illnesses and disorders covered by the mandate of the INMHA present an immense burden of disease. In this section, we provide summaries of the burden of disease for neurosciences, mental health and addiction. Many of the conditions which we have reviewed have a high prevalence in young to middle-aged adults, thus impacting on productivity, family life and future generations.

The diseases and disorders that we present here are only some of the most common ones which fall under the umbrella of the INMHA. We hope to be able to develop research on other, less common neuro-psychiatric disorders in due course and in collaboration with appropriate partners.

Data on burden of disease for the Canadian population are not always available. In some cases, extrapolation is made of data for the U.S. population. This situation highlights the fact that additional epidemiology research on burden of disease in the Canadian population is required in order to better define the scope of the problem.

Magnitude of the problem

Altogether, neurological and psychiatric conditions, including addictions, account for 1.4% of all deaths and 1.1% of years of life lost worldwide. However, the Global Burden of Disease Study[2], commissioned by the World Health Organization, the World Bank and Harvard University, demonstrates clearly that disability plays a central role in determining the overall health status of a population.

The leading causes of disability are shown to be substantially different from the leading causes of death. This casts serious doubts on the practice of judging a population's health from mortality statistics alone. For instance, the Global Burden of Disease study indicates that psychiatric and neurological conditions account for 28% of all years lived with a disability (YLDs) worldwide. The burden of psychiatric and neurological conditions is even higher in established market economies, such as

[1] A number of sources were used to compile this information. Please refer to the INMHA office for a list of references.

[2] Murray and Lopez, The Global Burden of Disease: A comparative assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Cambridge Mass.: Harvard School of Public Health, 1996.

Canada. Most significantly, the study shows that the burden of neuro-psychiatric conditions has been seriously underestimated. The estimated years of life with disability (YLDs) for the ten leading causes of disability in established market economies in 1990 are indicated in the following table. Eight of the ten leading causes of global YLDs related to neuro-psychiatric disorders and accounted for 44,8% of all YLDs. Unipolar depression alone was responsible for 13.6% of all YLDs in established market economies.

Leading causes of disability in established market economies - 1990 (both sexes, all ages)		
	YLDs (millions)	% of total YLDs
Unipolar depression	6.7	13.6%
Alcohol use	4.5	9.1%
Osteoarthritis	2.7	5.5%
Dementia and neuro-degenerative disorders	2.4	4.9%
Schizophrenia	2.2	4.5%
Bipolar disorder	1.7	3.5%
Cerebrovascular disorder	1.6	3.2%
Diabetes	1.5	3.1%
Obsessive-compulsive disorder	1.5	3.1%
Drug Use	1.4	2.9%

Alcohol Abuse

According to the 1993 General Social Survey (GSS), nearly one in ten adult Canadians (9.2%) reported having problems related to alcohol consumption.

In 1992, the health, social and economic costs of alcohol use to Canadian society were conservatively estimated at $7.52 billion or $265 per capita. This represents 41% of the total costs of substance abuse. The most important economic costs of alcohol use are $4.1 billion for lost productivity due to illness and premature death, $1.36 billion for law enforcement and $1.3 billion in direct health care services.

Alzheimer's Disease and Dementia

One in 13 Canadians over age 65 is affected by Alzheimer's Disease and related dementia. The number increases to one in 3 for people over age 85.

For Alzheimer's Disease alone, one in 20 Canadians over age 65, and one in 4 over age 85 are affected. With an ageing population, the risks for developing Alzheimer's Disease will increase.

It is estimated that in 2001, 109,000 Canadians age 65 and over will have been diagnosed with dementia. Of these, 70,200 will be women and 39,7000 will be men.

Costs associated with the care of people with Alzheimer's Disease are based on use of nursing home care, use of medications, use of community support services by caregivers and unpaid caregiver time. The annual societal cost of care per individual with Alzheimer's Disease is estimated to be:

- $36,792 for severe disease;
- $25,724 for moderate disease;
- $16,054 for mild to moderate disease;
- $ 9,451 for mild disease.

Overall, an estimated $5.5 billion a year are spent on people with Alzheimer's Disease and related dementias in Canada.

Amyotrophic Lateral Sclerosis (ALS)

Over 3000 Canadians currently have ALS, which can strike at any age. Once diagnosed, life expectancy is approximately 2-3 years.

The direct and indirect costs of ALS to the Canadian economy remain to be investigated.

Anxiety Disorders

North American epidemiological research indicates that lifetime prevalence rates for experiencing any anxiety disorder range from 10.4% to 25.1%. The lifetime prevalence rates for specific anxiety disorders range from 3.5% for panic disorder to 13.3% for social phobia.

A recent study reported a one-year prevalence rate for anxiety disorders, in general, in Ontario of 9% for men and 16% for women.

The direct and indirect costs of anxiety disorders to the Canadian economy remain to be investigated.

American data, however, provide some information. One study found that individuals with anxiety or depressive disorders cost an average of $2390 ($US) over a six-month baseline period, compared to $1397 ($US) for those without anxiety or depressive diagnoses.

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD, the most commonly diagnosed childhood behavioural disorder, occurs in 3% to 5% of school-age children. Boys are four times more likely to be diagnosed with ADHD than girls.

In the United States, children with ADHD use significantly more health care resources and incur significantly greater per capita total costs than children without ADHD ($1465 vs. $690; 1997 data). Co-existing mental health disorders substantially increase the cost of treatment for ADHD.

The direct and indirect costs of ADHD to the Canadian economy remain to be investigated.

Autism and Pervasive Developmental Disorders

Incidence of autism and pervasive developmental disorders (PDD) is estimated at 2-5 cases per 10,000 individuals although some studies suggest rates as high as 20 cases per 10,000. On a national basis, this would translate into a potential number of 60,000 Canadians with autism or PDD.

Average lifetime costs are evaluated at more than $2 million per person with autism when service or treatment is ineffective or inaccessible. Seventy-five percent of lifetime costs can be avoided for those who experience significant improvement of their condition when accurate early diagnosis, effective treatment and adequate support are provided. Fifty percent of lifetime costs can be avoided, on average, when accurate early diagnosis, effective treatment and adequate support are provided to all people identified with an autism condition.

Brain Tumours

10,000 new cases are diagnosed every year. National data on cost of care are not available, but a Nova Scotia study for the period 1996-1998 found that the mean cost of medical care for a patient with glioblastoma multiforme, from time of diagnosis to death, was estimated to be $17,149.

The direct and indirect costs of brain tumours to the Canadian economy remain to be investigated.

Cerebral Palsy

Extrapolating from U.S. surveys and data, there would be approximately 66,000 Canadians with cerebral palsy.

The direct and indirect costs of cerebral palsy to the Canadian economy remain to be investigated.

Drug Abuse

Rates of illicit drug use are much higher for males than for females (10.1% vs. 4.9%), and rates of use decrease progressively with age from 25.7% among those 15-17 years of age to less than one per cent for those aged 55 or older. As with heavy alcohol use, the demographic profile of an illicit drug user is generally that of a young, unattached male. Those who are single or never married are more likely to report illicit drug use (18.7%) as compared to 3.8% of the divorced, separated or widowed and 3.3% among those who are married.

In 1992, the annual economic costs of illicit drug use in Canada were estimated at $1.37 billion or $48 per capita. The largest cost (approximately $823 million) relates to lost productivity due to illness and premature death, and a substantial portion of the costs ($400 million) is for law enforcement. Direct health care costs due to illicit drug use are estimated at $88 million annually.

Eating Disorders

An estimated 0.5% to 3.7% of women suffer from anorexia nervosa; 1.1% to 4.2% will suffer from bulimia in their lifetime. Approximately 90% of cases of anorexia and bulimia occur in females. Binge eating effects both men and women and has a prevalence rate of 0.7% to 4%. Health care data indicate that a high mortality rate and major medical and psychiatric co-

morbidity rates are associated with eating disorders, especially anorexia.

In the United States, the average length of stay for women with anorexia who received inpatient treatment was 26 days with a mean cost of $17,384; the cost for a patient suffering from bulimia with an average length of stay of 14.7 days was $9088. Most episodes of care, as expected, are in an outpatient setting. The average costs associated with these treatments were $2344 for anorexia and $1882 for bulimia.

The direct and indirect costs of eating disorders to the Canadian economy remain to be investigated.

Epilepsy

Epilepsy is far more common than most of us realize, affecting about 300,000 Canadians, or approximately 1% of the population. 14,000 new cases, or 1 Canadian in 2,000, are diagnosed on average every year. 3,200 are children under the age of 10, and close to 4,000 are over the age of 60. In effect, more than 50 % of new patients are young children and senior citizens.

Although Canadian data on the cost of epilepsy are not available, an American study estimated the cost of this condition to be approximately $12.5 billion, with indirect costs accounting for 85% of the total. Extrapolated to the Canadian population, this would translate into an annual cost of approximately $1.25 billion.

Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Effects (FAE)

Health Canada indicates that, based on estimated rates in industrialized countries of 1-3 per 1,000 births, at least one child is born with FAS in Canada each day. Initial studies also indicate that the rates of FAS/FAE in Aboriginal communities are higher. Foetal alcohol syndrome is associated with life-long neurological, behavioural, social and cognitive problems. It is also associated with other physical and organ abnormalities.

U.S. data indicate that estimated lifetime extra health, education and social services costs associated with the care of an individual with FAS are $1.4 million U.S.

Gambling

Most Canadians gamble without experiencing any significant or long term problem. For a small minority however, gambling can be especially problematic and even pathological. According to the Canadian Problem Gambling Index: Final Report (February 19, 2001), 2.4% of Canadians present a moderate risk and 0.9% have serious gambling problems.

Calculating the financial and social costs of problem and pathological gambling is difficult. Some costs arise from treating problems directly, but many costs are indirect, such as gambling-related ailments, absenteeism at work and time spent in courts. One U.S. study estimated the cost at $13,200 U.S., while a 1996 study by a University of Manitoba researcher indicates that compulsive gamblers each cost society an average of $56,000 C.

Hearing Disorders

It is estimated that 3 million Canadians have hearing problems.

The direct and indirect costs of hearing problems to the Canadian economy remain to be investigated.

Huntington Disease

One in every 10,000 Canadians has Huntington Disease.

The direct and indirect costs of Huntington disease to the Canadian economy remain to be investigated.

Learning and Communication Disorders

Approximately 3 million Canadians have learning disabilities.

The direct and indirect costs of learning and communication disorders to the Canadian economy remain to be investigated.

Migraine

Approximately 17% of the Canadian adult population suffer from migraine, as well as 200,000 to 300,000 children. Several studies have reported that approximately 15-20% of women and 5-6% of men around the world suffer from migraines.

A recent study estimated that direct and indirect costs related to migraine represent more than half a billion dollars annually in

the Canadian economy, and more than 5.4 million workdays are lost each year. In the U.S., migraine costs the American taxpayers $13 billion annually in lost work days or reduced productivity. Extrapolated to the Canadian population, this would translate into an annual cost of approximately $1.3 billion.

Mood Disorders

Mood disorders encompass major depressive disorder, dysthymic disorder and bipolar disorder. Nearly twice as many women (12%) as men (6.6%) are affected by these conditions.

Nearly twice as many women (6.5%) as men (3.3%) are affected by a major depressive disorder each year. Five percent of the Canadian workforce suffers from depression, and the cost, including job loss, lower productivity, absenteeism and health care costs associated with depression is estimated at more than $3.5 billion annually.

In a recent Canadian study[1], the estimated total burden of disease of mental health problems, specifically depression and distress, were evaluated at $ 14.4 billion in direct and indirect costs.

Multiple Sclerosis

An estimated 35,000 – 50,000 Canadians have multiple sclerosis, the most common neurological disease affecting young adults in Canada. Canada has one of the highest rates of multiple sclerosis.

A 1998 study conducted by The Canadian Burden of Illness Study Group estimates that the annualized societal costs per patient in 1995 were $14,523 for patients with mild severity, $21,698 for the intermediate group and $37,024 for the severe group. In all severity groups, from 77% to 88% of the financial burden is borne by the patient. Indirect costs, namely lost daily activity/leisure time and lost productivity, were major societal cost drivers. The lifetime cost of multiple sclerosis, including institutionalization, was estimated to be $1.6 million per patient.

With the current estimated prevalence of multiple sclerosis, and based on an estimated average cost of $29,000 per patient per year, the annual cost of this disease to Canadian society is about $1 billion.

[1] Stephens, T., Joubert, N. The Economic Burden of Mental Health Problems in Canada, *Chronic Dis Can* 2001; 22 (1):18-23

Muscular Dystrophy

Approximately 10,000 Canadians suffer from muscular dystrophy or related problems.

The direct and indirect costs of muscular dystrophy to the Canadian economy remain to be investigated.

Pain

Surveys indicate that over 18% of Canadians suffer from severe chronic pain. The annual cost of chronic pain, excluding social costs but including medical expenses, lost income and lost productivity, is estimated to exceed $10 billion.

Parkinson's Disease (PD)

Little data exists on the prevalence and incidence of PD in Canada. The Parkinson Society of Canada estimates that approximately 100,000 Canadians suffer from PD.

The direct and indirect costs of Parkinson disease to the Canadian economy remain to be investigated.

Parkinson's disease is estimated to cost the U.S. economy more than $25 billion a year in direct health-related expenses, disability costs and lost productivity. Extrapolated to the Canadian population, this would translate into an annual cost of approximately $2.5 billion.

Posttraumatic Stress Disorder (PTSD)

PTSD is the fifth most common psychiatric disorder. It can affect anyone who has experienced serious trauma, been victimized, has witnessed a violent act or has been repeatedly exposed to life-threatening situations. PTSD can therefore affect survivors of rape or sexual assault, domestic abuse, physical attacks, car accidents, school or workplace violence, natural disasters, armed conflict and, of course, terrorist attacks and war.

Data relating to the U.S. population indicates that an estimated 70% of adults have experienced a traumatic event at least once in their life, and up to 20% of these develop PTSD. Women are twice as likely as men to develop PTSD. According to data from the National Institute of Mental Health, approximately 3.6% of the American adult population aged 18-54 years will suffer from

PTSD in a given year. The estimated lifetime prevalence of PTSD is 7.8%.

PTSD sufferers have a high rate of health care service consumption. However, PTSD sufferers often do not seek professional help because they do not associate their symptoms with a past traumatic experience or they feel helpless as to where to seek help.

The direct and indirect costs of posttraumatic stress disorder to the Canadian economy remain to be investigated.

Schizophrenia

It is estimated that 300,000 Canadians, or 1% of the population, will be diagnosed with schizophrenia at some point in their lives.

Schizophrenia costs Canadians more than $4 billion annually, $2.3 billion of which are direct health care costs and $2 billion are indirect costs.

Sleep Disorders

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the true prevalence of primary insomnia, primary hypersomnia, circadian rhythm sleep disorders, nightmare disorder and sleep terror disorder is unknown. The prevalence of breathing-related sleep disorders associated with obstructive sleep apnea is estimated to be 1-10% in the adult population, but may be higher in the elderly population.

According to the National Commission on Sleep Disorders Research (1992), 40 million Americans are chronically ill with various sleep disorders and an additional 20 to 30 million experience intermittent sleep-related problems. Extrapolated to the Canadian population, this would translate into 4 million and 2-3 million Canadians respectively.

There are no well-established data on the health, social and economic costs of sleep disorders and sleep deprivation. However, the Commission was able to definitely assign $15.9 billion as the direct cost of sleep disorders and sleep deprivation, with an estimated $50 to 100 billion in indirect and related costs, when the cost of individual accidents associated with sleep disorders and sleep deprivation are assessed, including litigation, destruction of property, hospitalization and death.

Extrapolated to the Canadian population, this would translate into an annual cost of approximately $1.6 billion in direct costs, and an estimated $5 to 10 billion in indirect and related costs.

Smoking and Tobacco Abuse

Smoking rates are 29.2% among the 15-19 age group, peak at 35.1% among those 20-24, then decline progressively within each age group to 33.7% (25-34 years), 33.4% (35-44 years), 28.3% (45-54 years), 23.7% (55-64 years), 17.2% (65-74 years) and 11.2% among Canadians aged 75 and older. Rates of smoking are higher among males than females (31.4% vs. 26.0%).

In 1992, tobacco abuse accounted for $9.56 billion in costs or $336 per capita and represents more than half (51.8%) of the total substance abuse costs. Lost productivity due to illness and premature death accounts for more than $6.8 billion of these costs. Direct health care costs due to smoking account for $2.67 billion.

Spina Bifida and Hydrocephaly

The incidence of spina bifida and hydrocephaly is estimated at one in 750 births in Canada.

The direct and indirect costs to the Canadian economy remain to be investigated.

Stroke

Stroke is a leading cause of death and of adult neurological disability. However, there are few data from which to determine the prevalence of stroke in Canada or the well-being of those who have been affected by stroke. According to a secondary analysis of data from the National Population Health Survey conducted by Health Canada in 1994-1995, 319 of the 58,439 people surveyed reported having experienced the effects of stroke. It can be extrapolated from these figures that there are 205,000 survivors of stroke in Canada, and 4.1% of people aged 65 and older are living with the effects of stroke.

Disability costs are not available for stroke. Health Canada (1997) conservatively estimated the total direct and indirect costs associated with stroke in Canada at $1.4 billion and $2.7 billion respectively, or a total of $4.1 billion annually.

Suicide

In 1997, the average suicide rate was 12.3 per 100,000 inhabitants (19.6 % for men and 5.1 % for women). The number of reported suicides in Canada in that year was 3681 (2914 for men and 767 for women). According to a cost-of-suicide analysis performed in New Brunswick, to our knowledge the only study of this kind in Canada, the mean total cost estimate per suicide death in 1996 was $850,000.

Traumatic Brain Injuries and Spinal Cord Injuries

There are, on average, more than 1000 new cases of spinal cord injuries and more than 36,000 new traumatic brain injuries each year in Canada. In 1994-1995, estimated annual costs for the 1150 new spinal cord injuries in Canada amounted to $184 million (acute care: $86.25 million; rehabilitation: $80.5 million; on-going care: $17.25 million). Estimated annual costs for the 36,015 new traumatic brain injuries amounted to $938.6 million (acute care: $361 million; rehabilitation: $144.4 million; on-going care: $433.2 million). Cost estimates for on-going care of existing injuries represent more than $15 billion annually.

Vision Disorders

The increase in the ageing population will bring about an increase in vision disorders and problems. The Canadian National Institute for the Blind is already recording an increase in the registration of clients with blinding eye diseases such as macular degeneration, glaucoma and diabetic retinopathy. Childhood disorders such as retinitis pigmentosa also lead to partial or total vision loss.

We don't know the true prevalence of blindness in Canada. A 1991 survey by Statistics Canada found 635,000 Canadians, or approximately 2.8% of the population, who identified themselves as having significant level of vision loss, even when wearing eyeglasses, that affects their daily living (30,000 were children aged 14 years and under).

Scholars have not yet done formal studies to estimate the cost of blindness in Canada. One informal attempt to develop an estimate based on techniques applied elsewhere and using figures from 1992, reported that in 1996, the cost of blindness in Canada was about $500 million. By 2016, the cost would climb by approximately 50% to about $750 million.

In the U.S. in 1981, the economic impact of visual disorders and disabilities was approximately $14.1 billion (U.S.) per year. By 1995, this figure was estimated to have risen to more than $38.4 billion - $22.3 billion in direct costs and another $16.1 billion in indirect costs each year.

4. STRATEGIC PRIORITIES

The INMHA's strategic priorities and research initiatives are in harmony with CIHR's four strategic directions, which are defined in its first national agenda on health research as:

- Building Canada's international leadership through national excellence in health research;
- Integrating the various disciplines of the health research spectrum, including life sciences, natural and social sciences, engineering, mathematics and the humanities;
- Improving the health status of vulnerable populations;
- Strengthening health research and the health system in the genomics era.

The INMHA has identified five priorities that it will pursue over the next few years in order to create and sustain a context for innovation. The first three priorities define the INMHA's research agenda and will help it develop the various initiatives that have been identified. The fourth and fifth can be viewed as enabling foundations that will help the INMHA structure, support and govern its activities.

The INMHA's strategic priorities are:

1. To foster and develop a capacity for innovation in research in neurosciences, mental health and addiction that will strengthen Canada's health research milieu in these fields and enhance its competitive position on the international scene. The four areas of focus are:

   1.1. Training;

   1.2. Strategic initiatives;

   1.3. Research in emerging areas or where unique opportunities are arising;

   1.4. Research in bioethics.

2. To pursue and sustain collaborative partnerships that will enable the INMHA to share, develop, obtain or leverage resources required to accomplish its mandate.

3. To promote linkage and exchange between the research community, the municipal, provincial and national levels of decision-makers, as well as users of research results, including non governmental and volunteer health organizations, through structured efforts aimed at knowledge translation.

4. To develop the INMHA's presence on the international stage through joint research, training and funding initiatives with scientific and research funding agencies in other countries.

5. To establish an organisational and an operational structure that will enable the INMHA to accomplish its goals. Three components have been identified:

   5.1 Effective governance and accountability;

   5.2 Communications;

   5.3 Health and research data and information.

5. RESEARCH PRIORITIES

In this section, we present an overview of INMHA's research priorities for the coming years. We present the general strategies and objectives as well as some of the actions that we have already taken and others that we intend to pursue.

In defining its initial research priorities, the INMHA identified those areas that were coherent with its mandate and critical to the accomplishment of its mission. It also sought to capitalize on existing scientific opportunities and collaborative efforts, and to address important health research concerns that could be approached in an inter-disciplinary manner.

5.1 Capacity for Innovation in Research in Neurosciences, Mental Health and Addiction

5.1.1 Training

The new context for research in Canada highlights the importance of exploring and implementing new mechanisms and methodologies aimed at providing training that will facilitate both trans-disciplinary and translational research.

Training constitutes an important element in the development of a research infrastructure. As such, both medium and long term commitment is required to sustain on-going training programs. The CIHR plays an important role in this respect. The INMHA recognizes its responsibilities in working with the CIHR and its other stakeholders in keeping this commitment.

Strategies

The INMHA will participate in the CIHR Training Grant Program by seeking to increase support through collaborative partnerships, at national and international levels, with other Institutes, interested governmental, non governmental and volunteer health organizations and Industry.

The INMHA will build research support capacity by creating opportunities for short-term training for clinician scientists, mid-career researchers, research associates and other research personnel. Accordingly, it will support trans-disciplinary training grant programs relevant to the INMHA.

The INMHA also recognizes that it plays a vital role in encouraging the future generation of researchers. The INMHA will therefore increase its visibility among young trainees (graduate students, post-doctoral fellows and residents) as well as potential trainees (high school students, undergraduate students). The INMHA will also acknowledge their efforts through various means.

Objectives

These strategies aim to:

- enable trainees to understand the complexity of diseases of the brain and of the mind, from their biomedical, clinical, behavioural and social components to their impact on population health and health services;
- sensitize trainees to the ethical issues related to research in the domains covered by the INMHA;
- incorporate new and emerging areas of knowledge from all four pillars into the INMHA trans-disciplinary training program;
- ensure the required level of funding through collaborative partnerships.

Actions

The INMHA has already carried out a series of actions that will enable it to rapidly pursue this priority. The INMHA has:

- elaborated a framework for capacity building for training in mental health services research, in conjunction with the Institute of Health Services and Policy Research;
- encouraged submission of training grant proposals in health services in neurosciences, mental health and addiction (in collaboration with the Institute of Health Services and Policy Research). A few postdoctoral training positions have been jointly financed for three years;
- collaborated with the Institute on Aboriginal People's Health on the competition for the creation of a training centre on mental health in Aboriginals. A training program on mental health and Aboriginal people's health has been evaluated and accepted (December 2001);

- established the BrainStar Award Program as a way to recognize the unique contribution of trainees to research in the domains covered by the INMHA. This Program was established in April 2001.

The INMHA will also:

- define a framework for trans-disciplinary training in neurosciences, mental health and addiction;
- further identify and define the areas of need and opportunity for trans-disciplinary training;
- define and develop new capacity building programs that meet the needs of researchers in the nursing, social sciences, humanities and rehabilitation sciences. A broad range of measures will be considered. These may include funding of:
  - release time from teaching;
  - sabbatical leave research stipends;
  - international conference travel awards;
  - career renewal awards;
  - short term exchanges.
- promote applications from both large and small research sites;
- provide financial support, in collaboration with other Institutes, government, non governmental and volunteer health organizations, provincial granting agencies and Industry, for additional training grants among pertinent applications that are highly rated through the CIHR Training Grant Program;
- support a workshop that will bring together leaders in clinical research in the areas of mental health, addiction and neurology. Discussions at this workshop should lead to the development of a unique national clinical training program in these domains.

The results of these actions will help define a multi-year trans-disciplinary training agenda that incorporates the target areas,

the number of training grants and the amount of funding required.

5.1.2 Strategic Initiatives

Strategy

The INMHA will promote and contribute to major research initiatives that will enable Canada's research milieu establish a leadership role at the international level.

Objectives

This strategy will lead to the development of innovative opportunities for cutting edge, cross-Institute and cross-pillar approaches to research in neurosciences, mental health and addiction. It will also help establish strategic partnerships that maximize financial, technological, research infrastructure and human resources investments in health research.

Actions

The INMHA will:

- establish a structure and a process for identifying and evaluating opportunities that constitute potential initiatives in the development of research capacity or knowledge. The INMHA foresees defining different funding mechanisms, according to the level of development required, which aim to ensure that sufficient capacity exists or can be developed to successfully pursue the initiative. As such, some strategic initiatives may be funded initially as pilot projects;

- put in place a process by which potential interest and initiatives with CIHR Institutes and other partners will be identified and negotiated. The INMHA has already supported several workshops/meetings with potential partners, including non governmental and volunteer health organizations, to explore possibilities, consolidate interest and define commitment. More workshops will be supported or conducted in the future.

To identify potential strategic initiatives in its first year of activity, the INMHA drew upon suggestions made by members of the Institute Advisory Board, the scientific community, non governmental and volunteer health organizations. Several

proposals were considered and the Institute Advisory Board decided upon the following four broad initiatives.

1. First episode in neurological and mental illnesses and in addiction

Recent evidence strongly suggests that appropriate diagnosis and effective treatment of the first episode of various neurological and mental illnesses, and possibly addictions, lead to much better clinical outcomes and improved quality of life for the patient and his/her family/social network. This is true not only for schizophrenia and depressive illnesses, but also for epilepsy, sleep disorders, alcohol abuse, stroke, and other illnesses or disorders. However, research in this area is still in its infancy. The potential is great in terms of developing new, ethically-acceptable diagnostic markers using gene identification, brain imaging, improved cognitive tests, hormonal status or ratings in stress-related situations - to name just a few - that may lead to the development of more appropriate, individualized therapies, improved quality of care, better health services and population health strategies. Early intervention strategies have also been shown to potentially lead to decreased rates of suicide and co-morbidity, to prevent the onset of secondary disorders and to improve functioning across a variety of personal, social and economic environments. With its universal health care system, Canada is in a unique position to be a world leader in the study of first episode events in brain-related diseases.

2. Co-occurrence of brain disorders with other health problems and co-morbidity

Co-occurrence of brain disorders with other health problems refers to the existence of any neurological, sensory, mental or addictive disorder in conjunction with health problems of another nature, for example cancer, diabetes, arthritis or respiratory problems. Co-morbidity is perhaps a better known condition within the spectrum of mental illnesses and addictions. However, neither co-morbidity nor co-occurrence of brain disorders with other health problems is sufficiently addressed in research.

Research in these fields is a major challenge for all scientists of the INMHA, and it is one that must be tackled in order to develop appropriate health care services. Initiatives in this topic should focus on:

- the identification of new tools to properly recognize and diagnose co-occurrence of brain disorders with health problems, and co-morbidity;
- the identification of new tools to evaluate outcomes of treatment;
- biomedical, clinical, socio-cultural and ethics research on mechanisms involved in the development of brain disorders associated with other health problems;
- research on the development of optimal clinical care and services.

3. Regenerative medicine - Neurosciences

Brain and spinal cord repair

Research in brain and spinal cord repair constitutes an area of intense activity, with major potential breakthroughs. New technologies (gene therapy, stem cells, trophic factors) are being developed rapidly and will lead to much improved treatments and, it is hoped, cures for various chronic neurological, neurodegenerative and neuromuscular diseases, brain tumours, spinal cord trauma, brain injuries, sensory disorders, or stroke.

Research in brain and spinal cord repair is a key area for the INMHA and one in which Canada figures as a world leader. Strategic research initiatives should range from biomedical to clinical research, ethics, quality of life and population health issues.

A joint strategic initiative on gene therapy for brain and neuromuscular diseases has already been negotiated and funded as an Interdisciplinary Health Research Team. This initiative is being funded under the leadership of the INMHA, with support from three other Institutes (Cancer, Human Development and Child and Youth Health, and Musculoskeletal Health and Arthritis) and in partnership with the Muscular Dystrophy Association of Canada and the NeuroScience Canada Partnership.

Vision and hearing losses

Major societal and economic costs are associated with various diseases and disorders related to vision and hearing. The ageing of the population and the higher incidence of blindness and deafness associated with other major health problems will lead to an

increased burden of disease. Most of the diseases associated with vision and hearing loss don't have any cures, and only some benefit from effective treatments.

The INMHA will focus on diseases related to vision and hearing loss, all areas in which Canada's research milieu is strong but under-recognized. There are several hundreds of vision and auditory health scientists scattered throughout Canada in many different universities and departments. We believe that this initiative will create an opportunity to mobilize and link scientists in collaborative programs that aim to attack the causes of vision and hearing loss. Research initiatives will most likely be multi-institute in nature.

4. Nicotine addiction and tobacco abuse

The burden of disease associated with tobacco abuse is extremely high – amongst the highest, according to Health Canada. Smoking and tobacco abuse in the general population is still increasing worldwide in spite of major campaigns to reduce it, and despite clear evidence that smoking directly increases risks for major or fatal diseases.

Innovative approaches to research are therefore required. The INMHA will focus on nicotine addiction, which is the major factor leading to tobacco abuse. Accordingly, a major pan-Canadian, CIHR-supported research initiative is being developed under the leadership of the INMHA, with the participation of all of the other CIHR Institutes and various non governmental organizations.

A Tobacco Summit will be held in Ottawa in Spring 2002 under the joint leadership of the INMHA, in partnership with all CIHR Institutes, and the Canadian Tobacco Control Research Initiative. All interested partners will participate in developing a National Priority Agenda on Research on Tobacco Abuse ranging from biomedical research to research on population health.

CIHR Strategic Initiative in Rural and Northern Health Research

The INMHA will also participate in the CIHR's initiative on building healthy rural communities. The CIHR initiative supports research and knowledge translation activities that contribute to improvements in health status, health systems and health resource utilization in rural Canada. The CIHR initiative targets

the development of research capacity, training and international research through appropriate partnerships and collaborations.

Other suggestions

As part of the strategic planning process, the INMHA has also received other suggestions from members of the scientific community. These will be reviewed in the coming months. They include:

- Developmental disabilities encompassing both childhood and adulthood;
- Genetics of complex behavioural/cognitive disorders;
- Mental health and primary care interfaces;
- Integration and management of mental health care and addiction services;
- Neurogenetics and epigenetic factors underlying addiction and mental illness;
- Decreasing suicide in Canada;
- Applications of computational and informatics technology to health care;
- Neural-prosthetic interfacing for vision and movement disorders;
- Occupational mental health.

5.1.3 Emerging Areas and Unique Opportunities

The nature of research is such that opportunities for development of new research areas or the timely growth of existing ones may arise at any given time depending upon the evolution of research findings, methodology or technology. The INMHA and other CIHR Institutes recognize the importance of nurturing such developments.

Strategy

The INMHA will promote and support New Emerging Team (NET) Programs, in partnership with other Institutes and interested national and international granting agencies as well as

governmental, non governmental and volunteer health organizations.

Objectives

In pursuing this priority, the INMHA seeks to:

- build research capacity by funding trans-disciplinary, innovative research teams on topics deemed of timely relevance to the mission and goals of the INMHA;
- establish a high level of partnership contributions.

Actions

Several actions have been carried out or are in progress. They include:

- consult the scientific community for identification of topics and establishment of priorities (carried out in Spring 2001);
- conduct discussions with interested Institutes, national and international granting agencies, governmental, non governmental and volunteer health organizations (on-going);
- conduct and co-sponsor workshops on rural and remote health, clinical research, risk taking behaviours and other topics of potential interest;
- support workshops to identify other potential topics. Workshops that have already been identified and will be supported include the development of unique animal models for stroke, sleep disorders-apnea (with the Institute of Circulatory and Respiratory Health) and circadian rhythm disorders;
- announce NET Programs competitions for Fall 2001.

The INMHA has identified the following themes:

1. Discrimination and Stigma

Discrimination and stigma are all too often associated with illnesses such as epilepsy, blindness, Parkinson's disease, autism, most if not all mental illnesses - especially schizophrenia, bipolar disorder and depression - and the majority of addictions, including alcohol and illicit drug abuse and gambling. As a consequence,

Canadians with neurological disorders, mental illnesses and addictions suffer not only from disease but also from prejudices that prevent them and their relatives, who are also affected by this situation, from seeking needed help or finding support in their community.

The INMHA, in collaboration with its partners, invites the creation of research teams aimed at finding innovative and effective means to reduce discrimination and stigma, and to raise public awareness about the impact of these diseases and disorders.

2. Understanding the Placebo Effect

Placebo responses are well-known confounding factors in the treatment of various illnesses. Placebo response is a significant component in the treatment of certain forms of pain, burn out and depressive illnesses. Placebo responses are also frequently observed in the treatment of neurological illnesses and addictive behaviours.

There are many examples of therapeutic effects arising from non-pharmacological healing contact, cultural or religious experience. On the other hand, modern techniques, such as brain imaging, have clearly demonstrated that placebo responses are associated with genuine cellular activation leading to modified pathophysiology.

The INMHA seeks the development of trans-disciplinary projects that will enhance our understanding of the nature of placebo responses in the treatment of diseases covered under the broad umbrella of the Institute. Innovative teams favouring the integration of disciplines ranging from basic neuroscience to social sciences and anthropology are particularly encouraged to apply.

3. Neurodevelopment and Early Life Events

The first months/years of life, and even the intra-uterine period, have a profound influence on the development of the brain and the nervous system. Early life events may manifest themselves over the long term as communication disorders, mental illnesses, addiction and suicidal behaviour, as well as through individual differences within the normal spectrum of functions such as response to stress and sensory functions. Early life events are also likely to contribute to the onset of disorders and illnesses such as

autism, attention deficit hyperactive disorders (ADHD), foetal alcohol syndrome (FAS), schizophrenia, depression, and others.

The INMHA, in partnership with the Institute of Human Development and Child and Youth Health, invites trans-disciplinary teams to submit innovative proposals aimed at understanding the impact of neuro-developmental insults and early life events on diseases and disorders covered by the mandate of the INMHA.

4. Computational Neurosciences and Artificial Intelligence

Computational neurosciences and artificial neuronal networks are rapidly evolving fields that should lead to the development of new means to treat speech, hearing and vision disorders or loss (through artificial voice, ear and eye mechanisms), to repair the injured brain and to provide key information on neuronal networking and patterning.

Canada is presently somewhat weak in these critical and high-potential research fields. Increased research activity could open the way to the creation of innovative products that have a substantial economic impact.

The INMHA, in collaboration with its partners, wishes to foster development in this domain by supporting innovative trans-disciplinary teams composed, preferably, of computer specialists, engineers, neuroscientists and clinicians. Partnership with the information technology industry is strongly encouraged.

Partnerships with other Institutes

Two themes have also been identified for partnership with other Institutes:

- Violence, gender and health across the lifespan, with the Institute of Gender Health and the Institute of Human Development and Child and Youth Health;
- Cognitive impairment in aging, with the Institute of Healthy Aging.

5.1.4 Research in Bioethics

Research in the domains covered by the INMHA presents important ethical challenges. At the present time, there is an increasing demand in clinical, academic, research and policy-making settings for people with sound training and research expertise in the field of health care ethics.

The INMHA acknowledges the central importance of both research in ethics and the ethics of research, and will strive to ensure that these priorities are addressed in all of its activities and research initiatives. INMHA-sponsored research must conform to the highest standards of ethical practice and be vigilant in its respect for, and protection of human and animal subjects of research.

In addition, funding for research in bioethics, particularly in neurosciences, mental health and addiction, is key to developing and ensuring good clinical and research practice in all areas within the purview of the INMHA. The INMHA is therefore committed to making bioethics research a priority focus both to advance knowledge in this area and to train our next generation of bioethics scholars.

Strategy

The INMHA will build research capacity in the area of health care ethics, in accordance with a central CIHR-lead strategy.

Objectives

In doing so, the INMHA aims to:

- promote and fund excellent research in health care ethics in the domains covered by the INMHA;
- increase the talent pool of people with sound training and established research careers in the field of health care ethics;
- provide service to other CIHR Institutes and organizations.

Actions

The INMHA will work with the CIHR in developing this component of its research strategy. The following actions have been identified:

- Partner with the CIHR in developing a framework for capacity building in bioethics, within existing CIHR programs and within the fields of interest to the INMHA, that would include the funding of:
  - career awards in health care ethics;
  - doctoral and post-doctoral awards in health care ethics;
  - operating individual or team grants.
- Support research initiatives focussing on particular challenges of the INMHA target population;
- Define and develop new capacity building programs that meet the needs of researchers in health care ethics whose training and research are in the field of humanities. Initiatives may include funding of:
  - release time from teaching;
  - sabbatical leave research stipends;
  - international conference travel awards;
  - strategic research networks (projects) in health care ethics;
  - career renewal awards;
  - retraining for faculty members to develop a research profile or to change domains;
  - short-term exchanges (professorship or internship).

5.2 INMHA's Presence on the International Stage

Given the possibilities that international collaborations provide, the presence of the INMHA on the international stage is essential if Canada is to benefit from today's context for scientific research and training in the domains covered by the INMHA.

Strategy

The INMHA will help Canadian scientists by promoting and developing joint research and training initiatives with institutes in other countries.

Objectives

This strategy will enable the INMHA to:

- develop and pursue collaborations in international research projects and funding;
- promote and establish trainee exchange programs at the international level.

Actions

Initial actions are a clear indication of the possibilities ahead. The INMHA has:

- created a focus group on International Affairs as part of its organizational structure (see section 5.2);
- visited various sister institutes at the NIH;
- met with representatives of the NIH and the John E. Fogarty International Center. Potential partnerships in research and training will be explored;
- participated in a conference on stigma at the Fogarty International Center;
- initiated and pursued discussions with other countries on the establishment of post-doctoral exchange programs. Discussions have been held with Japan and Israel. The focus of the exchange program with Japan encompasses more than neuroscience research and includes all aspects covered by the INMHA, with trans-disciplinary research and training being encouraged. An open call to potentially interested young Canadian scientists is already on the INMHA Web site. The first two postdoctoral trainees from Japan started in November 2001. A joint scientific meeting between Israel and Canada to discuss topics covered by the INMHA and to officially recognize collaborations is planned for December 2002.

The INMHA will also explore possibilities for joint collaborations with international pharmaceutical companies and biotechnology firms.

5.3 Linkage and Exchange - Knowledge Translation

Knowledge translation of research on prevention and treatment of illnesses and disorders covered by the INMHA is essential in order to develop evidence-based clinical care and services that meet the health needs of Canadians.

Strategy

The INMHA has defined several strategies:

- Collaborate with the CIHR in developing a framework for contributing to public policies and programs at the municipal, regional, provincial or national levels that will help create an environment conducive to the development of the CIHR and its Institutes;
- Engage in structured, individual activities that promote linkage and exchange;
- Develop a comprehensive stakeholder knowledge translation strategy aimed at:
  - Establishing interactive mechanisms by which potential users of research results and decision-makers would be informed of the potential application of research findings;
  - Facilitating knowledge translation, from basic research to health care services and new, innovative treatments of diseases and disorders;
  - Engaging potential users of research results and decision-makers in the development of the INMHA's strategic research agenda;
  - Involving decision-makers and stakeholders in action research (process).

Objectives

The INMHA seeks to play an important role in knowledge translation within its domains. The INMHA aims to:

- contribute to knowledge translation of research developed within the INMHA;

- gain financial support for research aimed at knowledge translation;
- promote transfer of research knowledge to evidence-based clinical interventions and services;
- obtain increased political and financial support for the activities of the CIHR and the INMHA;
- assist in the development of INMHA indicators on research outcomes.

Actions

Knowledge translation is complex. As such, several actions have been defined that will guide the INMHA in effectively attaining its objectives. Actions, some of which have already been carried out, include:

- work with the CIHR in developing a framework for knowledge translation in the domains of interest to the INMHA, including knowledge transfer to clinical/health services applications;
- support research grants on knowledge translation in the domains of interest to the INMHA. A Research Funding Application is already posted on the INMHA Web site;
- conduct workshops with governmental, non governmental and volunteer health organizations, and the pharmaceutical and biotechnology industries to further define objectives and actions for knowledge translation;
- participate in a CIHR committee on developing strategies vis-à-vis the Federal Government; participate in other committees as occasions arise;
- explore the interest of the CIHR in developing and funding knowledge-brokering activities in order to increase the INMHA's organizational capacity to support knowledge translation activities;
- encourage presentations to members of Parliament and governmental Standing Committees of interest to the INMHA. A presentation was made to the Standing Senate Committee on Social Affairs, Science and Technology in June 2001 by the Canadian Alliance on Mental Illness and Mental

Health (CAMIMH). The CAMIMH was represented by a member of the Advisory Board of the INMHA;

- undertake individual actions aimed at informing the policy-making community of financial and research organization issues of concern to the INMHA. Members of the Institute Advisory Board and INMHA Management have initiated meetings with members of the House of Commons and have already addressed presentations in the context of regular or special consultations undertaken by the Federal Government, including the Standing Committee on Finance during the 2001 pre-budget consultations in October 2001;

- conduct or support forums or workshops aimed at raising awareness among research users and decision-makers in order to promote linkage and exchange, knowledge transfer and knowledge translation;

- establish mechanisms or programs aimed at developing the skills and infrastructure required in linkage facilitation and knowledge transfer.

6. ENABLING FOUNDATIONS

In addition to developing and pursuing its research priorities, the INMHA is placing emphasis on two key functions that will help structure and support its research priorities, and ensure effective management of its resources.

6.1 Collaborative Partnerships

The context in which the INMHA has been created encourages collaborative partnerships aimed at sharing, developing, obtaining and leveraging resources required to achieve the Institute's goals.

Strategies

The INMHA has defined the following strategies:

- Collaborate with the Strategic Partnerships and Alliances as well as the Industry Programs Branches of the CIHR in identifying and developing potential partnerships;
- Develop sustainable partnerships with other Institutes and with governmental organizations at the municipal, provincial, national and international level as well as with non governmental and volunteer health organizations;
- Collaborate and partner with non governmental and volunteer health organizations in efforts aimed at enhancing:
  - Advocacy;
  - Information dissemination;
  - Knowledge translation;
  - Training;
  - Leveraged funding;
  - Surveillance;
  - Community support.

Objective

One primary objective arises from this strategy. It is to obtain the necessary and complementary human, financial and technological

resources that the INMHA requires to successfully develop its strategic initiatives, NET programs and training programs.

Actions

Proposed actions are diverse in nature and are in keeping with the diversity of the partnerships to be developed with municipal, provincial, national and international stakeholders. Actions include:

- Invite the INMHA's scientific community to identify existing or potential opportunities for partnerships;

- Conduct workshops with non governmental and volunteer health organizations to identify and develop existing or potential collaborative partnerships. One Round Table Discussion was held in Ottawa in June 2001 and two more are being organized for the coming months in Eastern and in Western Canada. The report from the first Round Table Discussion is on the INMHA web site;

- Hold joint Annual Meetings with representatives from the scientific community and non governmental and volunteer health organizations. The first Annual Meeting is being planned for Fall 2002;

- Pursue discussions with representatives from Japan, European and other countries in order to build on existing networks and to develop new networks;

- Initiate and pursue discussions with the National Institutes of Health in order to develop networks and possible funding collaborations;

- Hold work meetings with representatives from the Strategic Partnerships and Alliances Branch and the Industry Programs Branch of the CIHR to:

  - present the research objectives and potential interests of the Institute;

  - develop mechanisms for identifying and pursuing potential interests and partnership opportunities with small, medium and large enterprises (pharmaceutical biotechnology industries);

- identify potential governmental entities and non governmental and volunteer health organizations with whom to foster partnerships in accordance with the objectives of the Institute;
- assist in the development of INMHA performance indicators.

- Work with Scientific Directors of other Institutes to:
  - identify areas of potential collaboration on initiatives;
  - discuss potential interest in developing them;
  - define the leadership, financial and other conditions of the partnerships.

6.2 Organisational and Operational Structure

The INMHA's organisational structure and operational processes must support the efforts and endeavours of the Institute, and ensure its accountability to CIHR and its other stakeholders. The pertinent strategies, objectives and actions for each of the three key components are detailed below.

1. Implement an effective governance, accountability and management structure and process

Strategies

- Develop a governance and management framework that seeks to optimize the contributions of the Institute Advisory Board in:
  - approving and monitoring the INMHA's mission, vision, goals and strategies;
  - establishing and monitoring the INMHA's ethical principles in accomplishing its mandate;
  - monitoring management processes and control;
  - facilitating communications to and from interested parties;
  - assessing the Board's effectiveness.

Objectives

- Ensure that the INMHA accomplishes its mandate and achieves its goals;
- Enable the Institute Advisory Board to effectively discharge its role and responsibilities;
- Achieve an appropriate balance of centralization and decentralization within the unique structure of CIHR;
- Enable the Institute Advisory Board to report on the INMHA's activities and performance (accountability).

Actions

CIHR is presently defining its organizational structure which will, in turn, influence the governance and management structure and processes of the INMHA. The CIHR structure will most likely be in place in early 2002. In Year One and early on in Year Two of its Strategic Plan, the INMHA will therefore:

- clarify the Institute Advisory Board's responsibilities in the organizational design of the CIHR;
- review the nature, mandate and composition of the INMHA's focus groups (committees) in order to ensure that they align with the needs, strategies and actions stemming from the Strategic Plan. The present focus groups have contributed to the organizational and operational structuring imperatives of the INMHA's first year of activity. These groups are:
  - Communications and Knowledge Transfer;
  - Ethics and Law;
  - Governmental Affairs;
  - International Affairs;
  - Partnerships with non governmental organizations and Industry;
  - Strategic Planning and Budget;
  - Training and Education.

- include in the composition of the focus groups, representatives from various stakeholders in order to enhance the capacity of the INMHA to pursue its endeavours;

- develop guiding principles for the conduct of Institute Advisory Board matters ;

- define the kind of information or reports that the Institute Advisory Board requires from Management, and the frequency of reporting;

- develop indicators (an Institute "Balanced Scorecard") that will enable the Institute Advisory Board to monitor the INMHA's performance with respect to its research agenda as well as other aspects of its strategic and short-term plans.

2. Develop and sustain structured communications efforts aimed at informing and gaining an understanding of the health and research issues related to the INMHA's domains

Strategies

- Develop a comprehensive stakeholder communication strategy aimed at:

  - Facilitating comprehension of the INMHA's role, mandate and contribution to society;

  - Promoting an understanding of the disorders and illnesses of interest to the INMHA;

  - Ensuring an understanding of the social and economic impact of the disorders and illnesses of interest to the INMHA;

  - Ensuring an understanding of the biological, clinical, social and economic impact of research in the domains covered by the INMHA.

Objectives

- Increase the visibility of the INMHA;
- Promote the role and mandate of the INMHA;
- Ensure continued financial and moral support for the INMHA;
- Facilitate communications with all of the INMHA's stakeholders;
- Contribute to efforts in helping reduce discrimination against Canadians suffering from disorders covered by the INMHA.

Actions

- Engage a communications officer (in place as of August 2001);
- Develop a communication framework and plan, in collaboration with the CIHR;
- Develop appropriate communications tools that will enable the INMHA to enhance its capacity to disseminate information on its activities;
- Conduct national workshops with governmental, non governmental and volunteer health organizations to build a positive and supportive relationship with these organizations;
- Work with governmental, non governmental and volunteer health organizations to develop an anti-discrimination strategy.

3. Develop a framework for gathering, maintaining and accessing relevant and reliable health and research information in the fields of interest to the INMHA

Strategy

- Collaborate in developing a data bank on timely, relevant and reliable health and research information of interest to the INMHA as a tool for results-based management and accountability frameworks.

Objective

- Ensure access to relevant and reliable information on:
  - burden of disease;
  - sources and amount of funding for scientific training and research in the fields covered by the INMHA;
  - municipal, regional, provincial and national organizations, foundations, commissions or committees in the fields of neurosciences, mental health and addiction;
- Develop specific performance indicators with respect to research in the fields covered by the INMHA on:
  - the impact which INMHA's support has had on the quality and quantity of research being conducted;
  - the expansion of the pool of trained and highly capable health research personnel;
  - the development and strengthening of partnerships and linkages between stakeholders in Canada's health innovation system;
  - the translation, communication and dissemination of research knowledge, its use and its impact on improved health and health care;
  - the leadership and co-ordination of INMHA with regard to national health issues.

Actions

- Work with the CIHR and other Institutes in identifying existing data and information required by the INMHA;
- Identify the gaps in data and information;
- Develop, with CIHR and other partners, information systems and data banks that facilitate access to relevant information;
- Incorporate, in all research funding applications, criteria for reporting progress on research and training activities funded by the INMHA;

- Participate in national and international meetings and scientific forums regarding issues of concern to the key areas covered in the INMHA's mandate in order to inform the INMHA of the most recent research and program developments in Canada and other countries;

- Work with the CIHR and other Institutes in defining a process and mechanisms for the development of performance indicators for research in the fields covered by the INMHA.

7. FUTURE CONSIDERATIONS

The strategic planning exercise which the INMHA has carried out with its stakeholders has enabled this new Institute to define a framework for the realization of its ambitious mission and its future development. We believe that our success in accomplishing the INMHA's mandate depends upon concerted efforts in identifying and developing the research priorities that the INMHA should address. Our success also depends a great deal on the establishment of collaborative partnerships at municipal, provincial, national and international levels that aim to actively support the Institute's endeavours.

The INMHA recognizes that the implementation of its Strategic Plan is a highly dynamic and evolutional process, much as research is. We hope therefore that the initial response that we have received in support of the INMHA's mandate will carry forward in the implementation of the Strategic Plan. In this respect, we invite members of the scientific community as well as our other stakeholders to participate with us in pursuing innovative opportunities that will enable the INMHA to be at the forefront of research in all fields covered by its mandate.

To succeed, we must to be truly innovative and creative, and seek to excel - in spite of the usual external constraints. Do not hesitate to contact us to explore future potential strategic initiatives and novel partnership opportunities for the INMHA. This is your Institute.

CIHR IRSC

Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

INMHA
Douglas Hospital Research Centre
McGill University
6875 Blvd Lasalle
Verdun, Quebec, H4H 1R3

www.cihr.ca

CAT. No. MR21-35/2005E
ISBN: 0-662-32395-5